Addressing Social Determinants of Health in People with Epilepsy

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Overview

• Inform about the needs of the population who has epilepsy
• Existing resources for people with epilepsy and self-management programs
• Project
• Results
• Future directions
About epilepsy

• Epilepsy is a complex condition characterized by recurrent seizures.
• Over 3.4 million people in the United States suffer from active epilepsy ~1 % of the population
• 65% of patients with seizures are not controlled with medications = 1,190,000 people with uncontrolled epilepsy

Epilepsy Specific Cost
$1,022 to $19,749 per person greater if uncontrolled greater with co-morbidities

Zack et al. 2017
Christensen et al. 2007
Begley et al. 2015
Emily

2001 (11 yo)
- Drug-resistant seizures with onset at 2 years of age after a non-febrile convulsive episode
- Seizures do not respond to medications
- Undergoes temporal lobectomy in 2002
- Seizure free after
- Medications are discontinued 1 year after surgery without recurrence of seizures
- Graduates high school and fulfills her dream of becoming a flight attendant, moves to Chicago

2014 (24 yo)
- Had to quit her job as flight attendant because of depression and cognitive problems
- Had anxiety attacks that were mistaken as seizures
People with epilepsy also face:

- Cognitive impairment and memory problems
- Complex medication regimens
- Lifestyle adjustments
- Symptom management
- Depression

- Under- or unemployment
- Educational deprivation
- Disability
- Limited access to transportation
- Stigma
More about persons with epilepsy

<table>
<thead>
<tr>
<th>Service</th>
<th>Active Epilepsy</th>
<th>No Epilepsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental care</td>
<td>14%</td>
<td>18%</td>
</tr>
<tr>
<td>Eyeglasses</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>Mental health</td>
<td>2%</td>
<td>8%</td>
</tr>
<tr>
<td>Prescriptions</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Transportation</td>
<td>2%</td>
<td>9%</td>
</tr>
</tbody>
</table>

In 2013, 12% of US adults said they would avoid a person with epilepsy who has frequent seizures.

Source: CDC: Epilepsy at a glance 2017

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Percentage of Adults with Active Epilepsy Who Saw a Doctor in the Past 12 Months

- Saw general doctor and specialist: 50%
- Saw general doctor but not specialist: 36%
- Saw specialist but not general doctor: 6%
- Did not see general doctor or specialist: 8%
The Managing Epilepsy Well Network (MEW)

Community of practice:
8 Collaborating Sites
- Epilepsy Foundation
- Center for Disease Control and Prevention
- American Epilepsy Society

Mission: Advance self-management research in epilepsy

- Conducts scientific research about self-management programs in randomized controlled trials
- Disseminates and implements programs with community partners
- Implements new technologies and distance delivery into care
Addressing Memory Problems in Epilepsy

Self-management program

- 12 week program utilizing problem solving therapy and self management to cope with memory problems
- Learning memory strategies
- Participant is assigned a memory coach
- Delivered over the phone to forgo transportation problems
- Easy to implement and has been shown to improve quality of life and memory in two randomized controlled trials

(HOme Based Self-Management and COgnitive Training CHanges Lives)

(Caller, 2016, Schmidt AAN 2019)
Project
The goal of this project

Hire, train, and integrate a specialized epilepsy community health worker (CHW) into the epilepsy center at Dartmouth-Hitchcock to address SDOH and promote self-management programs.
Social determinants of health (SDOH)

• “Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.” (1)

• By some estimates, up to 80% of a person’s health is determined by these factors, NOT by the medical care they receive. (2)


How do social determinants of health impact people with epilepsy?

• Half of all people with active epilepsy have an annual family income of less than $25,000.
• Nationally, there is an estimated $15.5 billion in annual medical costs and reduced earnings from people with epilepsy.
• Children with seizures are more likely to live in poverty, and their parents are more likely to report food insecurity.
• People with epilepsy face significant transportation barriers as all states have laws that restrict drivers’ licenses for persons with seizures.
• An estimated 20-50% of people with epilepsy also experience cognitive problems, and these problems are associated with low quality of life, high disability, and high medication noncompliance.
Project planning

• Interviews with key clinic staff to develop workflow and referral system
• Roles defined
• Data collection methods finalized
• Appropriate trainings for CHW identified
• Education of providers and potential referral sources:
  • Provider education at weekly epilepsy conference
  • Materials sent to administrative and clinical staff
HOW CAN WE HELP YOU?

Our Community Health Resource Specialist can help you navigate a number of issues. Please check all that apply:

- Baby & family support services
- Behavioral health
- Child care
- Dental
- Education
- Employment
- Financial assistance
- Food insecurity
- Health education
- Health insurance
- Housing
- Intergenerational safety
- Legal
- Medical home
- Transportation

WE ARE HERE TO HELP

Charlie Bangsma
Epilepsy Community Health Resource Specialist

About Charlie:
Charlie lives in New Hampshire for 12 years and has worked for local community mental health care organizations and in alternative school settings.

Contact:
Charlie.Bangsma@Hitchcock.org
603-655-9523

WHAT IS A COMMUNITY HEALTH RESOURCE SPECIALIST?

A Community Health Resource Specialist, or Community Health Worker (CHW), is a part of your care team. Working in clinics and out in the communities they serve, CHWs link you with local social services or other applicable support. They bridge the gap between community resources and clinical care.

Charlie Bangsma joined the Epilepsy Center as a CHW in August 2019. Charlie is specially trained to help with issues related to epilepsy.

YOUR HEALTH IS MORE THAN THE CARE YOU RECEIVE.

- Where people are born, live, learn, work, play, worship, and age, affect health and quality of life, whether they know it or not.
- While seeing your doctor or healthcare provider and getting treated for illness is important, it is also important to address other factors that impact overall health, such as stable housing and food access.

WHAT IS OUR GOAL?

Our goal is to improve the overall health and well-being of our patients, not just through medical care, but also by addressing social factors that impact health.

HOW DO YOU USE THIS SERVICE?

Your epilepsy provider can make a referral to our CHW. For more information on what type of issues can be addressed, please see the list on the back of this brochure or contact us.

We will contact you directly once your provider has made a referral.

Please note that these services are not considered medical care.

AN EXAMPLE OF A COMMUNITY HEALTH RESOURCE SPECIALIST IN ACTION:

- Identifying barriers to stable housing
- Using their knowledge of systems to source different options for the patient
- Offering assistance in filling out, reviewing, and sending housing applications to multiple homes around town
- Attending housing meetings with patients
- Being available throughout process both in person and via phone (direct contact) until the patient is in secure housing

Affordable housing is an area of critical need for many people. Community Health Workers are able to serve patients in this area by:

Administrative Coordinator
Morgan D. Maclean
Morgan.D.Maclean@Hitchcock.org
603-655-9423
Hiring & Training

General CHW Training:

There is no formal accredited CHW training program in the state of NH.

Training was provided by the DHMC CHW program in the Population Health Department, as well as external trainings in mental health first aid, etc.

Epilepsy Training:

The Centers for Disease Control and Prevention:
The Community Health Worker’s Training Curriculum for Epilepsy Self-Management

• 3 sessions, 6 hours
• Delivered by subject matter experts from DHMC and the Epilepsy Foundation

Trained as HOBSCOTCH coach
Referrals

• Patients were referred by clinical and non-clinical staff in the Dartmouth-Hitchcock Epilepsy Clinic. Staff were asked to refer patients that identified one or more need from a set list of categories. Secretarial staff were asked to refer patients who had missed appointments.

• The CHW contacted patients directly to determine what needs were present, and begin helping them address their needs.
Pathways

• Pathways Community Health Hub is an evidence-based method for addressing and documenting patient needs. “Pathways” are opened when a certain type of need is identified, and they have standardized time frames and endpoints so that needs are met and documented consistently.

• Types of pathways that can be “opened” and “closed”:
  • Baby & family support services
  • Behavioral health
  • Child care
  • Dental
  • Education
  • Employment
  • Financial assistance
  • Food insecurity
  • Health education
  • Health insurance
  • Housing
  • Interpersonal safety
  • Legal
  • Medical home
  • Transportation
Results
Results

• All results included in this analysis are limited to patients enrolled before April 2020 (IRB until then)
• Patients enrolled during project period n=53
• Patients closed/completed during project period n=24
• CHW connected PEW to HOBSCOTCH (n=4) and helped deliver the program (n=3)
### Patient Characteristics

Table 1. Patient characteristics for the whole sample and for closed patients only.

<table>
<thead>
<tr>
<th></th>
<th>Entire sample (n=53)</th>
<th>Closed patients (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, No. (%)</td>
<td>28 (52.8)</td>
<td>13 (54.2)</td>
</tr>
<tr>
<td>Mean age, years</td>
<td>47.4</td>
<td>47.3</td>
</tr>
<tr>
<td>Marital status, No. (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>30 (56.6)</td>
<td>14 (58.3)</td>
</tr>
<tr>
<td>In a relationship</td>
<td>17 (32.1)</td>
<td>8 (33.3)</td>
</tr>
<tr>
<td>Declined to answer</td>
<td>1 (1.9)</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Unknown/missing data</td>
<td>5 (9.4)</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Insurance Type, No. (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>28 (52.8)</td>
<td>13 (54.2)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>25 (47.2)</td>
<td>12 (50.0)</td>
</tr>
<tr>
<td>Private</td>
<td>15 (28.3)</td>
<td>7 (29.2)</td>
</tr>
<tr>
<td>None</td>
<td>2 (3.8)</td>
<td>2 (8.3)</td>
</tr>
<tr>
<td>Employment, No. (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>10 (18.9)</td>
<td>5 (20.8)</td>
</tr>
<tr>
<td>Not working</td>
<td>37 (69.8)</td>
<td>16 (66.7)</td>
</tr>
<tr>
<td>Unknown/missing data</td>
<td>6 (11.3)</td>
<td>3 (12.5)</td>
</tr>
</tbody>
</table>
### Table 2. Insurance detail – all patients accounted for only once.

<table>
<thead>
<tr>
<th>Insurance type, No. (%)</th>
<th>Entire sample (n=53)</th>
<th>Closed patients (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare only</td>
<td>11 (20.8)</td>
<td>3 (12.5)</td>
</tr>
<tr>
<td>Medicaid only</td>
<td>11 (20.8)</td>
<td>4 (16.7)</td>
</tr>
<tr>
<td>Medicare and Medicaid</td>
<td>14 (26.4)</td>
<td>8 (33.3)</td>
</tr>
<tr>
<td>Private only</td>
<td>12 (22.6)</td>
<td>5 (20.8)</td>
</tr>
<tr>
<td>Private and public</td>
<td>3 (5.7)</td>
<td>2 (8.3)</td>
</tr>
<tr>
<td>None</td>
<td>2 (3.8)</td>
<td>2 (8.3)</td>
</tr>
</tbody>
</table>
Referral Sources

Nurses and APRNs referred the majority of patients
Pathways Opened

- Transportation
- Health Insurance
- Financial Assistance
- Health Education
- Housing
- Food Insecurity
- Client-specific goal
- Interpersonal safety
- Employment
- Behavioral Health
Reasons for Closure

- Completion of program: 18
- Lost to followup: 5
- Client withdrawal: 1
- Other - lack of available jobs: 1
Missed clinic appointments and phone calls to the clinic

Table 2. Average missed clinic appointments and phone calls to the clinic, pre and post CHW intervention (n=24)

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone calls per month, average (SD)</td>
<td>0.56 (0.66)</td>
<td>0.78 (1.39)</td>
</tr>
<tr>
<td>Missed visits per months, average (SD)</td>
<td>0.053 (0.09)</td>
<td>0.008 (0.04)</td>
</tr>
<tr>
<td></td>
<td>1.5/3 months</td>
<td>0.3/3 months</td>
</tr>
</tbody>
</table>
Post-COVID patients

• N=12 (referral dates 3/24 – 6/18)
  – 8 of these patients opened a single pathway, 4 of which were completed
  – CHW was not able to connect with 4 of these patients

Types of pathways opened since beginning of COVID-19

Other goal
Financial...
Health insurance
Transportation

0 1 2 3 4 5

Other goals:
• Find therapist (2)
• Find neuropsychiatrist
• Find mental health treatment center

CHW could be utilized to connect to mental health resources
Final numbers

- Participants referred N=65
- 17% lost to follow up (n=11)
Lessons Learned & Future Directions
Lessons Learned

• Educating existing staff on the CHW role in order to promote referrals was challenging.

• Our referral workflow did not facilitate referrals from providers (ie, providers were expected to refer when a patient identified a need appropriate for the CHW). A more standardized way of referring should be utilized in the future.

• Our CHW was physically located in the research building, rather than in the clinic. In future projects, we believe better proximity is important for promoting visibility of the CHW and consistent referrals.

• It was challenging for the CHW to work with patients with cognitive problems. Many patients forgot who the CHW was and/or the work they were doing together.

• The CHW needs more experience with self-management programs to feel comfortable with delivery.
Future Directions

- Continue implementation work to install CHW in epilepsy clinics and work with local agencies to utilize CHW for epilepsy
- Continue to collect data – larger sample sizes and better quality data
- Expand to other neurologic conditions
- We received additional funding from the CDC to develop models for implementation of CHW in epilepsy clinics
Further info

www.managingepilepsywell.org

HOBSCOTCH.org and the HOBSCOTCH Institute
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